

Missing out

The identification challenge



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Summary

For many people, looking after an ill, older or disabled loved one doesn't have a name, it is 'just something you do'. However, not recognising you are carrying out a caring role can be a real barrier to accessing vital support.

If you do not see yourself as a carer, then you are unlikely to consider asking for a carer's assessment, applying for Carer's Allowance, or seeking advice from others who find themselves in similar circumstances. Not recognising you are caring means missing out on help, advice and information, with serious personal and financial implications.

Based on findings from Carers UK's State of Caring Survey 2016, examining the experiences of over 5,682 current carers – this research explores the time it takes for people to recognise they have taken on a caring role, and whether they had missed out on support because they simply didn't think of themselves as a carer. The research also looks at the impact that missing out on support can have across carers' lives.

The findings are stark. They demonstrate that the majority of carers take years to recognise their role, missing out on crucial financial, practical and emotional support in the meantime. This research demonstrates that, by not receiving support at an early stage, the negative impacts of caring are intensified with many carers missing out on benefits and entitlements and others forced to give up work altogether. On a personal level, a lack of practical help can have a huge impact on health and wellbeing, from long-term physical health effects such as back pain, to mental ill health and social isolation and as a result of caring without a supportive network.

The longer it takes to identify as a carer the more likely it is that carers will struggle without the support and advice they need. Frontline professionals, such as GPs, social workers and pharmacists play a central role in ensuring carers are identified and then guided to support as early as possible in their caring journey. Under the Care Act 2014, local authorities and health bodies in England must work together to identify carers¹

and any carer who appears, or is likely to have, needs for support must be identified and offered a Carer's Assessment. The Social Services & Well-being (Wales) Act 2014 and the Community Care & Health (Scotland) Act 2002 include similar measures to ensure carers are identified and guided to support. In Northern Ireland, the Carers and Direct Payments (NI) Act 2002 states that Health and Social Care Trusts must work to identify carers.

The good news is that in some areas the time taken for people to identify their caring role has shortened in the last 10 years. This means that awareness and identification work is having an impact, but evidence from carers demonstrates there is still much more to be done.



¹ Department of Health Care and support statutory guidance, Paragraph 2.35
<https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>

Key findings

The majority of carers take years to recognise their caring role:

- Over half of carers (54%) took over a year to recognise their caring role
- Almost one in four carers (24%) took over 5 years to identify as a carer, and nearly one in ten (9%) took over 10 years.

Some groups of carers, such as parent carers, mental health carers and distance carers, take longer than average to identify their role.

Not recognising a caring role is a significant barrier to accessing support:

- 91% of carers said they missed out on financial or practical support (or both) as a result of not identifying as a carer.

The impact of missing out on support due to not identifying as a carer is significant:

- Half of carers (50%) said that missing out on support had an impact on their physical health
- Three quarters of carers (78%) suffered from stress and anxiety as a result of missing out on support
- 3 in 5 carers (61%) said missing out on support put a strain on their relationships with friends and family
- For half of carers (52%) missing out on support impacted negatively on their finances
- 2 in 5 carers (42%) said missing out on support had caused them to give up work to care.

Nation view

Scotland:

- **56% of carers** took over a year to recognise their caring role. **26%** took over 5 years to identify as a carer.
- **51% of carers** said that missing out on support, due to not identifying as a carer impacted negatively on their finances, **50% of carers** said their physical health had suffered.

Wales:

- **55% of carers** took over a year to recognise their caring role. **24%** took over 5 years to identify as a carer.
- **57% of carers** said that missing out on support, due to not identifying as a carer impacted negatively on their finances, **55%** of carers said their physical health had suffered.

Northern Ireland:

- **58% of carers** took over a year to recognise their caring role. **29%** took over 5 years to identify as a carer.
- **48% of carers** said that missing out on support, due to not identifying as a carer impacted negatively on their finances, **52%** of carers said their physical health had suffered.



Why is identification important?

Carers provide unpaid care by looking after an ill, older or disabled family member, friend or partner. As a society we are increasingly dependent on the contribution of carers.

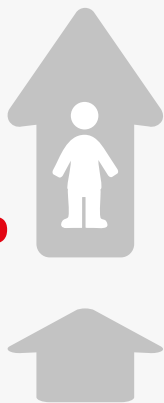
We have an ageing population, often with complex care needs, and a health and care system that is struggling to keep up with demand.

Recent Carers UK research² shows that the contribution made by those who provide care is growing, with both the numbers of people providing care, and the amount of care being provided, increasing significantly.

There are **6.5million carers** in the UK³

Since 2001
the number
of carers has
increased by
16.5%

This vastly
exceeds
population
growth (6.2%)⁴



Each year, carers support
in the UK is worth

**£132
billion⁵**



By 2017, the number of
older people needing
care will outnumber
family members able
to meet that need⁶



Every year 2.1 million people take on a caring role.⁷ As more and more of us find ourselves looking after someone, it is essential that as a society we recognise those undertaking a caring role and their need for support. Providing care can have a huge impact, often turning family life upside down if the caring role comes about suddenly or intensifies quickly. While many carers find their role rewarding and want to be there to support their loved ones, looking after someone can take a serious toll on carers' health and wellbeing, finances, ability to work and relationships with other family members and friends. Too often carers are only identified when they are struggling to manage or are in crisis, with consequences for our already stretched health and social care system.

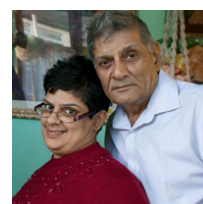
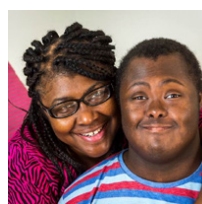
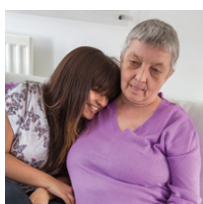
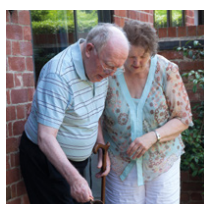
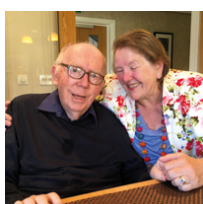
By identifying carers, we can:

- Help carers to look after their own physical and mental health
- Provide access to financial support and entitlements
- Support carers to stay in work
- Reduce isolation and loneliness
- Reduce pressure on health and care services
- Improve outcomes for the person receiving care
- Reduce the risk of carers reaching breaking point
- Positively support families and relationships.
- Support carers to continue their studies and remain in education

² Carers UK (2015) *Valuing Carers: The Rising Value of carers support*; ³ Census 2011; ⁴ Carers UK (2015) *Valuing Carers: The Rising Value of carers support*; ⁵ ibid; ⁶ Linda Pickard (2013) *A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032* is published in *Ageing and Society*; ⁷ Carers UK (2014) *Need to know*

The identification challenge

Despite the large number of people providing care, many who take on caring responsibilities simply do not see themselves as carers. They are just a husband or wife, son or daughter, parent or friend, doing what they can to support someone close to them.



We know having the right information at the right time can make a huge difference when you are looking after someone.

Helping carers to identify their caring role unlocks access to information, advice and support. If you don't see yourself as 'a carer', you won't seek out advice and information that is labelled 'for carers'. This means those carers who do not recognise their caring role are missing out on vital support - often early on in their caring journey when it is most critical. It can also mean that important choices and decisions about managing care, such as reducing hours at work, are made without the knowledge of the full picture of support available.

"When I initially became a carer I was unaware of the help available in any form, therefore coping with caring and full time work stretched all aspects of life."

"Because you are not aware of the help and support you can ask for then you just get on with things until they get too hard then you start to find out things."

Missing out on support due to not identifying as a carer can also mean carers struggle to cope with the demands of caring, making their role unsustainable and increasing the risk of reaching breaking point, where they are overcome by exhaustion, suffering physical and mental breakdown.

"There has been an enormous impact on the family as a whole. We have coped but it has been extremely difficult at times. We have reached breaking point several times."

Every caring role is different and there are a number of reasons why people do not always see themselves as a carer:

- For some the pressures or intensity of caring means they neglect their own needs, and don't stop to consider the role they are undertaking.

"I think I was more focused on the lack of suitable care for my husband in the early stages. I was convinced that I would be able to cope if he had proper help."

“

When I initially became a carer I was unaware of the help available in any form, therefore coping with caring and full time work stretched all aspects of life.

”

“

I had no idea what people meant when they talked of carers becoming ill through caring. I think I was probably reluctant to be defined as a carer.

”



- People often see themselves primarily as a friend or family member - a wife or husband, son or daughter, mum or dad, and don't feel the need for another label, or to put themselves 'in a box'.

"As she was a child I saw myself as just mum not a carer"

- People with less intense caring roles can feel that they do not 'warrant' or deserve recognition for the role they undertake.
- The word 'carer' itself can be barrier, with some feeling it can imply dependency, burden or even an obligation to care.
- Confusion about the term 'carer' can also make it difficult, with the word often being used interchangeably within health and social care settings to describe paid staff such as care workers.
- Sometimes carers do not realise the impact caring has, or the amount of care they provide.

This can often be the case when caring increases gradually over a long period of time. As one carer said:

"It's difficult to establish the point when the relationship changed from popping in to see your parents are okay, to full-time carer..."

For some carers, calling themselves a 'carer', is vitally important and they feel that it gives value to their role. Many campaigned for recognition and feel that it more clearly defines what they do to health and care professionals.

At times, it can be useful to use the term 'carer' particularly when talking more in depth about rights, entitlements or benefits such as Carer's Allowance.

Who can help identify carers?

Frontline professionals such as doctors, pharmacists, social workers, teachers, and Job Centre staff play a critical role in helping people to recognise they are caring and signpost them to advice and information services or their local carers' organisation.

Under the Care Act 2014, introduced in April 2015, local authorities and health bodies in England must work together to identify carers, and similar duties are in place in Scotland. Across the UK, national legislation sets out the duties that local authorities have to identify and support carers. In England, a Carer's Assessment must be offered to any carer who appears, or is likely to have, needs for support. In Wales an assessment must be offered if the carer appears to have a need for support and, in Scotland and Northern Ireland, carers who provide regular and substantial care have a right to a Carer's Assessment.

Across the nations, Carer's Assessments should look at the impact of a caring role on all aspects of a carer's life and what support they and their family need. It should also make clear what is available to support them locally and whether they are entitled to local authority funded support.

Carers UK believes a new duty on health and education professionals to identify and support carers should be introduced. This would embed the principle of supporting carers into day-to-day practice helping to change culture and raise awareness of caring.

Employers can also help to identify those in the workplace with a caring role and can play a key role in guiding employees to support. Carers UK's employer forum, Employers for Carers (EfC), brings together over 110 businesses to make the case for supporting carers in the workplace. Among other benefits, membership of EfC provides organisations with information, advice, toolkits and workplace sessions for line managers including guidance on identifying and supporting carers at work.

Other ways that employers can help in identifying carers include:

- Raising awareness of caring through events, the staff intranet and displaying posters in common areas
- Gathering information about caring responsibilities through, staff surveys and workplace awareness events
- Including information about caring in staff handbooks, policies and procedures
- Identifying carer champions within the workplace.

Employers in Scotland can find support, information and advice through Carer Positive – an award scheme administered by Carers Scotland on behalf of the Scottish Government, which recognises employers who support carers in their workforce.



NHS England and identifying carers

As part of its Commitment to Carers, NHS England recently released new guidance for health professionals on implementing an integrated approach to the identification, assessment and support of carers in NHS settings. The document suggests NHS staff ask the following questions to those presenting in health settings:

- Do you look after someone who couldn't manage without your help and support?
- As a result of you being here having (medical) treatment would you be able to continue that care?
- Will you need any extra support because of your own health needs/medical treatment which we are discussing today? (if the answer to this question is "yes" the carer should be asked what support they need)
- Are you willing/able to continue your caring role?

“

Where the carer identifies they are in need of support, or may need support in the future, the healthcare practitioner should seek to establish what needs the carer may have as it may be possible to meet these needs during the consultation. Where this is not possible, the carer should be asked if they are aware of the local carer support organisation and, if not, referred to the local carers' support organisation. If social care or carer support practitioners are identifying a health need as part of their carers assessment they should have the ability to refer the carer back to their GP for health support.

”

NHS England (2015) An integrated approach to identifying and assessing carer health and wellbeing

Mary Makinson, 65, from Epsom

Mary has been caring for her husband with Parkinson's, and her son who has mental health issues for around 10 years, but only identified herself reluctantly as a carer over 8 years ago when her son was first hospitalised and health professionals referred her. She just saw herself as a wife and mother.

Caring has been challenging and stressful at times and she had to give up work as a supply teacher – a job she loved.

“

As a supply teacher, I got to choose my hours. But when caring became more demanding and stressful, I turned down work because I just couldn't get enough sleep or I needed to travel to health appointments.

Only after a particularly bad episode eight years ago when my son Andrew was in hospital did health professionals identify me as a carer and refer me for support. Caring leaves little time for me so having access to a carers support group and counselling has really made a difference to me

”



Research findings

This research is based on responses from over 5,682 current carers to Carers UK's 2016 State of Caring survey.

The majority (82%) were caring, full-time, for more than 35 hours a week. The results reflect the responses of carers from across the UK (78% from England, 9% from Scotland, 8% from Wales and 5% from Northern Ireland).

Time taken to identify as a carer

- **Over half of carers (54%)** took over a year to recognise their caring role.
- **Almost one in four carers (24%)** took over 5 years to identify as a carer, and **nearly one in ten (9%)** took over 10 years.

Positively, there has been an increase in the number of people who recognised their caring role within the first year of providing care, compared with similar research conducted by Carers UK in 2006.⁸

Nearly half (46%) of those who responded to this question in 2016 recognised their caring role within a year, compared to 36% of people in 2006 – a 10% increase. This suggests that awareness campaigns like Carers UK's Carers Rights Day, Carers Week, and local work is having an impact on new populations of carers.

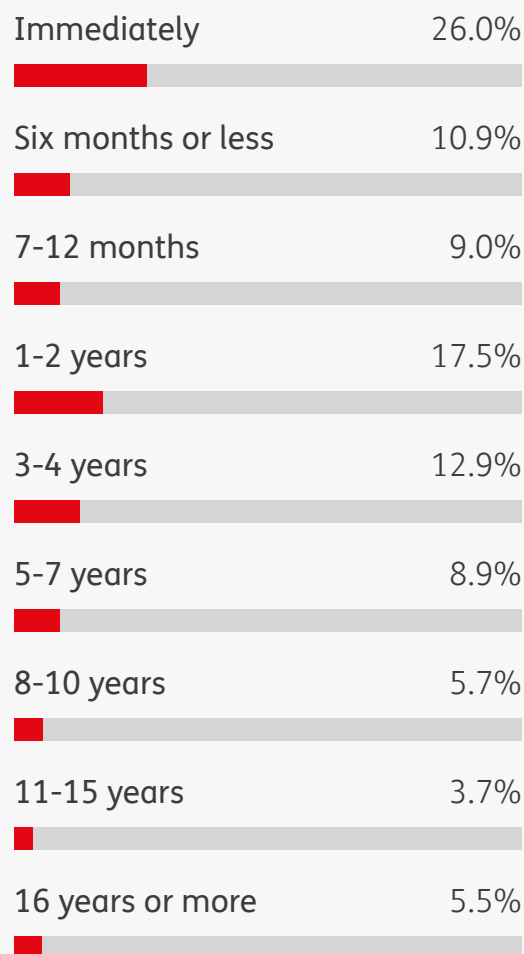
Over half

54%

of carers took a year to recognise their caring role.



“How long did it take you to recognise yourself as a carer?”



⁸ Carers UK (2006) *In the know: The importance of information for carers*.
N.B The data used in the 2006 study is a small sample however reflects a similar cohort

Some groups of carers with common characteristics are more likely to take longer to identify as a carer:

Parent carers

Those caring for a disabled or seriously ill child took longest to identify themselves as carers. They were much less likely than average to identify themselves immediately as a carer and significantly more likely to take longer to identify their role.

- More than one in three parent carers (37%) took longer than 5 years to recognise themselves as a carer.

For many parent carers it can take a long time to get a diagnosis for their child, or can take time for the severity or characteristics of a condition to become apparent, as the child grows older. The delay in identification may also be because parent carers are more likely to see themselves as simply 'mum' or 'dad' rather than as a carer.

"As my son was disabled from birth, initially I was Mum of a young child but eventually realised that this will go on for ever and I was both Mum and carer."

"Our son was born with Down's Syndrome so I always knew he would need more support, I just didn't realise how much until he was 3-4 and still unable to do the things my other 2 children could."

Over a third

37%



of parent carers took longer than five years to recognise themselves as a carer.



Mental health carers

Those caring for someone with a mental health condition took significantly longer than average to identify as a carer:

- **28%** of mental health carers took 5+ years to identify themselves.

For many, caring is perceived as being a physical role – helping lift and dress someone, or helping the person receiving care use the toilet, for example. In contrast, mental health carers are more likely to be co-ordinating support, helping with paperwork and finances and providing emotional support, and this can act as a barrier to recognition.

"When my husband has been severely mentally ill I have to supervise him around the clock - he might withdraw money and overspend or say or do something he will later regret."

More than one in four

28%



of mental health carers took longer than five years to identify themselves as a carer.

Distance carers

It takes people longer to identify as a carer if they live a significant distance away from the person they provide care for. For many carers, caring at a distance can mean providing more intermittent care, characterised by periods of intense caring, for example over a weekend, and care from a distance that involves coordinating care and providing emotional support. This group of carers took second longest to identify themselves as carers.

- **30%** of those who live more than two hours away from the person they care for took 5+ years to identify as a carer.

Three in ten

30%



who live more than two hours away took longer than five years to identify as a carer.

Why identification matters: access to advice and information

A significant majority of carers miss out on vital support as a result of not recognising that were caring:

- **91% of carers said they missed out on financial or practical support (or both) as a result of not identifying as a carer**

The impact of missing out on support is exacerbated by the amount of time carers take to identify their role. The longer it takes to identify as a carer, the more likely it is that carers are missing out on support and advice.

Those who identified themselves as a carer immediately or within 6 months were less likely to say they missed out on support:

- **34% of those who identified as a carer within 6 months felt they didn't miss out on support, compared to 7% of those who took 5+ years to recognise their caring role.**

Missing out on support as a result of not recognising a caring role can have a significant impact across carers' lives, leaving carers facing financial hardship, poor health and anxiety.

Physical Health

Caring can be physically demanding – for many it might mean lifting the person needing care, helping them dress, wash and move around the house. As such, carers need practical support and equipment to help them care safely and well, and to avoid injury. For example, the use of hoists or home adaptations such as stairlifts can help ease the physical strain of moving and handling loved ones.

- **Half of carers taking part in this research (50%) said that missing out on support, due to not identifying as a carer, had an impact on their physical health.**

Trying to manage without the right support and equipment can exacerbate existing health conditions and result in long term physical strain. The GP Patient Survey highlights the impact of caring on carer health – whilst 51% of non-carers had a long-standing health condition this rose to 63% of all carers and 70% of carers caring for 50 or more hours a week. The survey also highlighted higher levels of arthritis, high blood pressure, and long-term back problems are more common amongst carers who provide hands on care.⁹ Indeed, those providing high amounts of care are twice as likely to be in bad health as non-carers.¹⁰

“What impact did missing out on support have on you?”

(Of those who didn't identify immediately)

It impacted negatively on my finances 52%



I had to give up work to care 42%



My physical health suffered 50%



I suffered stress or anxiety 78%



It put a strain on my relationship with the person I care for 46%



It put a strain on my relationships with other people 61%



Without the right support to look after themselves, and the replacement care to ensure they have the ability to attend their own health appointments or even time to exercise, carers physical health problems can escalate resulting in long term injury which jeopardises their ability to carry on providing care.

■ *“I just feel exhausted”*

■ *“I feel tired worn out and shattered but keep going with a smile and a lot of crying on my own.”*

■ *“My general health and wellbeing have suffered and I will soon need a carer of my own.”*

Half of carers

50%

said that missing out on support, due to not identifying as a carer, impacted on their physical health.



⁹ Carers UK (2015) *Facts about carers*; ¹⁰ Census 2011

Mental health and relationships

Alongside the physical strain of caring, the expectation and isolation caring can bring makes carers particularly vulnerable to poor mental health.

Of carers taking part in this research who missed out on support as a result of not recognising their caring role:

- **3 in 4 carers (78%)** suffered from stress and anxiety as a result
- **3 in 5 carers (61%)** said missing out on support put a strain on their relationships with friends and family

While caring can be very rewarding and carers often share how valuable they feel their role is, they can also feel resentment about the difficult situation they find themselves in, resulting in stress and anxiety. Those undertaking very significant caring roles can find it very difficult to maintain relationships, and 8 in 10 carers have felt lonely or socially isolated as a result of their caring responsibilities.¹¹ Carers often describe how their 'world shrinks' with caring taking up so much time and energy that they simply don't have the time to meet up with friends. Money can also be an issue – in a recent Carers UK survey 64% of carers who said they are struggling financially are cutting back on seeing family and friends.¹²

Once carers have identified their role, they are able to seek support from services such as counselling or psychological services, although often these can be difficult to access. Peer support, such as the Carers UK forum, can provide a lifeline, allowing carers to share what they are going through with others in similar situations.

"You tend to isolate yourself as the stress and tiredness you feel everyday exhausts you physically and mentally."

"Am losing touch with friends and feel an outcast. Never get asked to social events now."

“

[Caring] had inhibited me having a relationship for 13 years. For 10 years as a carer I did not know respite care, or any other 'help' existed. It came to light after a visit to A&E when I was introduced to Age UK.

”



Three in five carers

61%

said that missing out on support, put a strain on their relationships with friends and family.



"Not having early support meant difficulties on agreeing with my wife over how to respond properly to the illness. This led to much stress. Our other two daughters found it difficult to come to terms as to what was happening to their sibling. Relationships in the family became strained and it wasn't until two years later, when we were introduced to a Carers group, that we started to learn about mental health conditions and become more accepting of the situation. We then learnt that we could have received Carer's Allowance for those first two years or so, which would have helped us greatly with our finances."

Three in four carers

78%

suffered from stress and anxiety as a result of missing out on support with caring.



¹¹ Carers UK (2015) *Alone and Caring*; ¹² Carers UK (2016) *State of Caring 2016*

Financial Support

Taking on a caring role can result in a sharp reduction in family income due to the extra costs of caring, with higher utility bills, transport costs and the cost of care services stretching finances to the limit. In Carers UK's recent survey of over 6,000 carers, 48% of those caring 35 hours or more said they were struggling to make ends meet.

Of carers who missed out on support due to not identifying as a carer:

- **Half of carers (52%)** said missing out on support impacted negatively on their finances

While it is the lowest benefit of its kind at only £62.10 per week, Carer's Allowance provides vital independent income and some contribution towards the extra costs of caring for those providing over 35 hours of care a week. Carers that are not able to claim Carer's Allowance may be eligible for Carer's Credit – a benefit that ensures carers entitlement to the State Pension by protecting National Insurance credits. A range of other benefits and entitlements, such as Income Support

Half of carers

52%

said that missing out on support, due to not identifying as a carer, impacted negatively on their finances.



and Housing Benefit, are available to carers in certain circumstances.

- Of those who missed out on financial support due to not identifying as a carer – **57.9%** are presently struggling to make ends meet (compared to **44%** of all carers).

This suggests that not getting the right support early on in a caring journey can have long term and continuing impact on household finances.

Employment

For those trying to juggle work and caring responsibilities, it can be really hard to 'keep on top of everything', with the emotional demands of providing care, and the day to day realities such as hospital appointments, making it difficult to combine the roles without support:

- **2 in 5 carers (42%)** said missing out on support due to not recognising their caring role had caused them to give up work to care.

When carers identify their caring role and the impact it is having, this can open up conversations with their employer about their commitments. Their employer might consider introducing flexible hours, or a temporary reduction in working hours to enable them to juggle their responsibilities. Some employers have a specific Carers Policy outlining the support available, which can include a period of Care Leave so that carers are not forced to take annual leave for caring emergencies.

"Lack of sleep was a huge factor and I often went to work having had no sleep. I hid a lot of my home life because many aspects of caring are extremely personal, but equally my bosses never bothered to enquire how I coped."

Two in five carers

42%

said that missing out on support, due to not identifying as a carer, had caused them to give up work to care.



Preventing carers from missing out

Recommendations

1 A new duty on the NHS and education professionals to put in place policies to identify carers and to promote their health and well-being.

While much good practice exists in health and education settings, for example through the use of 'carer champions', a duty on health and education professionals would ensure a step change in culture, ensuring professionals take a 'whole family' approach to their work that embeds carers as expert partners that can help to achieve better outcomes. This is a key ask from Carers UK for the new Carers Strategy for England, currently in development.

2 Development of education, information and training for a range of frontline professionals to increase knowledge and signposting of carers.

To be able to identify, signpost and support carers when they come into contact with them, professionals need to understand the demands of a caring role, know what they can do to help, and where best to signpost carers to.

3 Improved access to information and advice for carers.

Navigating the maze of benefits and entitlements alongside trying to work out the complex health and social care system can be extremely difficult. Ensuring carers have access to relevant, high quality information is essential. However, only 35% of carers in England who had Carer's Assessment in the last year felt that the support they need to look after their physical and mental health was properly considered.¹⁴

Improved access to information and advice should also include improving provision for specific carer groups – particularly, BAME carers, carers who are themselves disabled and male working age carers.

Local authorities should use the information and advice and prevention mechanisms in the Care Act 2014 in England, and co-operation with the NHS to ensure that carers are identified and referred to information and advice.

4 Employers should look at measures they can take to identify and support carers in the workplace.

1 in 9 UK employees has caring responsibilities¹⁵, yet many face a lack of understanding from colleagues and managers. To support carers to remain in work, businesses can join Employers for Carers, an employer led forum which provides practical advice and support for employers seeking to develop carer friendly policy and practice. In Scotland, the Carer Positive scheme awards employers who support carers, recognising the importance of retaining experienced members of staff, reducing absence, and cutting down on avoidable recruitment costs.

5 Public awareness campaigns to improve understanding and recognition of caring.

While professionals play a central role in identifying carers, everybody has a part to play in ensuring their social networks, family, friends and colleagues are supported if caring. By increasing recognition of the value of providing care amongst wider society, we can help to improve wider understanding and recognition of carers huge contribution.

¹⁴ Carers UK (2016) State of Caring



Carers Rights Day

Carers UK runs Carers Rights Day every year where we are joined by hundreds of organisations raising awareness of caring, helping to identify carers and signpost them to information, advice and support.

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